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SPECIAL REPORT

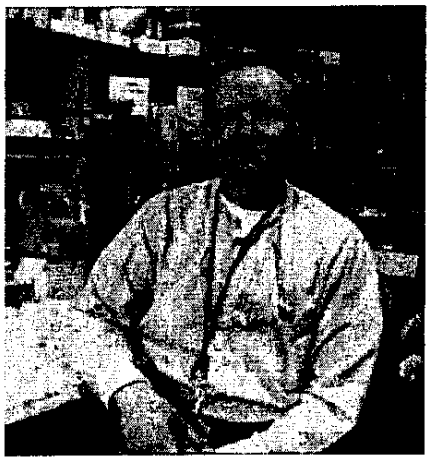
Trials & Tribulation

In the Name of Science

By Joanne Cavanaugh Simpson

David Elliott tossed back a small cup of live bacterium. After taking his dose, the Hopkins graduate student in pathology joined several others in a conference room, where he waited for an hour in case of an adverse reaction. The chatty group tried to describe just what the dose tasted like. It wasn't exactly chalk, but...

The live bacterium they ingested delivered a single HIV protein. And the people in the room were healthy volunteers getting paid about $40 a visit to take several doses over a year in a human clinical trial at Hopkins's Center for Immunization Research. The study was conducted a year and a half ago, part of ongoing research into a possible vaccine for the AIDS virus.



Grad student David Elliott regularly volunteers for medical studies.
Photo by Will Kirk

For weeks after taking each dose, the volunteers--graduate students, staff, community members--recorded their temperatures four times daily, came to the center to get physical exams, and kept a log of every medication they took. Elliott and the others were told they could not contract the AIDS virus from the protein but were warned they might develop a flu-like illness. If their bodies produced antibodies in response to the test vaccine, they might falsely test positive for HIV--a potential problem when it comes to health insurance.

The volunteers' total monetary compensation: about $600 each. But, for Elliott, the payoff is much greater. "With AIDS being one of the great killers of humans, I strongly feel we need a vaccine, " he says. He has watched friends die from the disease. "If I was told I might feel crummy for a few days, would that be worth it?" he asks. "Sure, it would be worth it if it would help to find a vaccine. I will do anything I can to help."

Elliott, 34, is one of the thousands of healthy volunteers who participate in clinical trials at Johns Hopkins. In the name of science he has been tilted backward on a table to monitor changes in his blood pressure (he fainted), and has taken doses of a hepatitis C antigen in a vaccine study.

When sick patients enroll in a clinical trial, they often harbor hope that they will derive benefit. Healthy subjects don't have the same incentive. They are driven instead by a variety of motives: a personal commitment to the scientific process, access to free medical tests, intellectual curiosity, the lure of novelty, some extra cash.

One primary research group that's tuned in to all of the above: graduate students. "We tend to do these things because we are interested in the research," says Elliott. "But I'd be the last person to tell you the check doesn't come in handy." Elliott, whose own research focuses on a waterborne parasite that can cause diarrhea, has found volunteering to be a two-way street. "I can't expect people to participate in my studies if I don't participate in theirs."

He and other Hopkins students and staff often trade tips on clinical trials, or peruse hallways and newsletters for notices of new studies. "Brain Imaging Study: SEE YOUR BRAIN AT WORK!" touted one flier posted recently at the East Baltimore campus.

"The first thing we talk about is how much it pays," says Susanna Kanther, a research coordinator in physical medicine and rehabilitation at Medicine. "Then we see whether it's worth it in terms of time and risk." Kanther, 23, says she avoids studies involving viruses or AIDS, or those that would leave permanent scars. Most medications are OK, though, if they are FDA-approved.

Kanther, Elliott, and other volunteers say that the staffers they deal with in studies are generally professional and caring, and have thoroughly explained any side effects or risks as part of the informed consent process.

They do have a few suggestions. The foremost: better on-the-job training for all who carry out the tests, especially in departments that don't regularly conduct human clinical studies. Some volunteers felt they occasionally weren't told enough about what was going to happen during the test, though bigger risks of the overall study were laid out. Other times, they weren't able to get quick answers about the scientific details of the study.

Kanther suggests more verbal follow-up to the written consent form. In mid-2001, she found herself concerned during a study at Bayview's Asthma and Allergy Center. "They were looking at asthma medication, what constricts the lung and opens it up," she says, noting the study was not the one in which Ellen Roche was enrolled. "I went into a room and breathed this stuff that made it harder for me to breathe, then I was told to blow out. It was getting harder for me to breathe and I was worried, 'Will it be reversed?' "

She had been told that a chemical was available to reverse the process if she became uncomfortable but was reluctant at first to ask for it. "I didn't want to sound weak," says Kanther, who was given the [reversing] chemical and has had no subsequent problems. Her advice: "Don't just rely on the subject to ask questions. They may not know what questions to ask."

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